

Scientific progress could be casualty in public health vs. privacy debate over newborn blood samples

November 7 2012

The tremendous potential public health benefits of research with blood samples left over after routine newborn screening must not be lost amidst controversy and litigation, say medical and bioethics experts in a commentary published in the journal *Science Translational Medicine*.

"The potential value to [biomedical research](#) for improving both public health and individual health must be part of the public discussion about what should happen to residual dried [blood samples](#) from [newborn screening](#)," says Michelle Huckaby Lewis, MD, JD, lead author of the commentary and Research Scholar at the Genetics and Public Policy Center of the Johns Hopkins Berman Institute of Bioethics. "The research community must advocate for policies that support the retention of these samples and their use in biomedical research."

Almost all of the 4 million babies born each year in the United States undergo mandatory screening that uses a small sample of blood to screen for certain [medical conditions](#) before the onset of symptoms, in many cases preventing needless suffering and death. The U.S. [Centers for Disease Control and Prevention](#) have hailed newborn screening as one of the most successful [public health](#) programs of the 21st century. Residual blood left over after the screenings is used for quality assurance purposes for state screening programs, but they also have been used for biomedical research.

Lewis notes that much of our current understanding about the [genetic modifications](#) that cause certain diseases - for example, some types of [childhood leukemia](#) - are a result of research using residual dried blood samples (DBS) leftover from newborn screening.

Lewis and her colleagues write, "We should be the generation that recognizes the potential value of these samples and commits to developing them as a resource to promote public and individual health. The scientific community has a responsibility to the nation and its citizens to use these resources ethically, but also to the fullest extent possible to improve the health of our citizenry."

Some parents in Minnesota and Texas objected to the state's use of DBS without parental permission and sued the states' Departments of Health, claiming that the state had violated their constitutional right to privacy. In 2011, a settlement of the Texas litigation resulted in the destruction of 5.3 million archived blood samples. The Minnesota Supreme Court ruled that written informed consent was required to retain DBS and use them for research, and in January 2012 the Minnesota Department of Health announced plans to begin destroying the left over samples as soon as newborn screening is completed.

The destruction of these samples may be detrimental to the highly effective state newborn screening programs but could also prevent important medical breakthroughs by making the research impossible, according to Lewis and her co-authors, Amy McGuire, JD, PhD, and Michael E. Scheurer, PhD, of Baylor College of Medicine, and Robert Green, MD, MPH, of Brigham and Women's Hospital and Harvard Medical School.

"In the future, newborn screening blood samples could be a major contributor to a better scientific understanding of how our genes impact our health over the course of our lifetime, for diseases ranging from

heart disease to cancer," Lewis says. "But the research cannot be done if the samples are destroyed."

The authors agree that the privacy concerns of parents are valid. The larger issue standing in the way of DBS research, the authors write, "is the erosion of trust in the research enterprise caused by violation of the basic ethical principle of respect for persons, as perceived by the parents."

Education should be a cornerstone of policies related to the retention and use of DBS, the authors write, "so that the public can learn about and better understand the potential benefit of research" using these important samples. "In this way, the loss of a valuable resource can be prevented and the public trust in the research enterprise can be restored."

Provided by Johns Hopkins University School of Medicine

Citation: Scientific progress could be casualty in public health vs. privacy debate over newborn blood samples (2012, November 7) retrieved 20 March 2024 from <https://medicalxpress.com/news/2012-11-scientific-casualty-health-privacy-debate.html>

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